"Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship"

Meeting: Tuesday April 16, 2019 3:30pm – 5:30pm
451 Junction Road
Madison, WI
UW West Clinic Room 1287
Enter the clinic… turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:
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Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue Madison, WI 53714-1815

Information Sources :
International Myeloma Foundation (IMF)
Phone: 800 - 452 - 2873
Email: TheIMF@myeloma.org
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Upcoming Meeting Speakers… Mark your calendars now!
Erin Costanzo, PH. D. UW Cancer Psychology department will join us for the June meeting.

Kelley Sidorowicz, IMF Support Group Regional Director will be our featured speaker at the August meeting.

Our Myeloma Support Group will be recognizing a milestone 20yrs in September. No speaker is planned. Leaving the time open for us to celebrate!

Dr Natalie Callander will likely join us for the October meeting.

Mark your calendars for the **3rd Annual Myeloma Patient and Caregiver Symposium** in Pewaukee, WI Saturday, September 28th. This is a great conference and you will not want to miss it. More info to follow.

Thank you to Larry and Mary Lou for their generous contribution to our group. It will be used for expenses related to the printing and mailing of our newsletter. It is greatly appreciated.

Condolences...

It is with great sadness that I share this news. Mary Polancih passed away in the early morning hours of Tuesday, March 19th. She passed peacefully in her sleep. It was not Myeloma that took Mary from us but a secondary cancer- AML Mary joined our group November 2011. She was our advocate working with the International Myeloma Foundation (IMF) to make a difference in cost of care and drugs. Mary was our go to person for many of the hard questions about this advocacy work, Medicare and transplants; as she had two of them.

Mary was a kind, compassionate and strong woman. As a former teacher, she was always trying to teach us something; especially me. I know I have learned a lot from her over these years. We will miss her .

The Promise Study is currently looking for people who don't have cancer but may have higher risks. It is the first study to broadly screen participants for blood cancers. The Promise Study offers free, easy screening to adults with family risks- those whose parent, sibling or child is diagnosed with myeloma or a precursor condition such as MGUS, Smoldering or Waldenstrom Macroglobulinemia. Visit their website to learn more or call 617-582-8544. Your family members may want to participate to help others and take charge of their own health. Dana-Farber Cancer Institute is supporting this effort.

Myeloma drug development -news from the IMF. Here is a look at the latest developments:

- **Selinexor:** It was announced on Friday, March 15, that the U.S. Food and Drug Administration (FDA) will now reach a conclusion about the new drug application for Selinexor by July 6, 2019 rather than by the original date of April 6. This delay is actually good news because following the 8 to 5 vote by the ODAC committee against approval, more time will be available to further review the issue. The FDA will get an early look at the data from the randomized BOSTON trial, in which selinexor is combined with Velcade plus dexamethasone (versus Velcade/dexamethasone alone). Results of both toxicities and early efficacy will be available. There is optimism that this review will tip the balance toward possible FDA approval of selinexor, despite the negative ruling by the ODAC committee.

- **Daratumumab subcutaneous:** The results of the randomized phase III COLUMBA study were recently released. In this study, daratumumab administered by subcutaneous (under the skin) injection was compared with the standard intravenous infusion administration. The results showed that in the relapsed or refractory setting, the overall response was 41.1 percent for subcutaneous daratumumab versus 37.1 percent for IV infusion daratumumab (meeting criteria for “non-inferiority” [marginally better]) for the subcutaneous administration.

  This is obviously very encouraging. In addition, no new safety signals were detected, and the subcutaneous approach appears to have been both convenient—it takes 3-5 minutes to receive a dose--and well-tolerated. Clearly, a submission for regulatory approval is imminent, and can lead to much preferred approach to daratumumab administration.

- **Panobinostat (Farydak):** Farydak is an HDAC (histone deacetylase) inhibitor already approved by the FDA (accelerated approval on February 23, 2015) for use in relapsed or refractory myeloma in combination with Velcade and dexamethasone. Farydak was developed and licensed by Novartis, who

has announced that the global rights to the drug have been acquired by Secura Bio, an integrated, commercial-stage biopharmaceutical company. The goal is to enhance availability of Farydak, and, potentially, to develop new dosages and drug combinations.

- **Venetoclax:** There is not such good news about the new agent venetoclax. On Tuesday, March 19, the FDA announced that they have put a hold on enrollment in myeloma trials, including those using venetoclax combinations. This decision is based on unexpected deaths in the venetoclax/Velcade/dexamethasone treatment arm in the randomized phase III BELLINI trial, in which Velcade/dexamethasone is the control arm or comparator. There were 21 percent deaths (41 out of 194 patients) versus 11.3 percent (11 out of 97 patients) linked primarily to infection. This result is surprising in that earlier venetoclax studies have shown improved treatment benefit without serious added toxicities.

  There is broad agreement that venetoclax is an important and helpful agent, especially for patients with the t(11;14) translocation, for whom there is striking single-agent activity. For the combination studies, greater caution will be required related to potential infections, and new guidelines are anticipated. Yet again, this BELLINI trial result emphasizes the need for randomized trials to fully assess both benefits and potential unexpected toxicities. Any off-label use of venetoclax should be accompanied by prophylactic antibiotics to prevent infection. In view of the unexpected increased risk of death in the BELLINI trial, any patient taking venetoclax both within and especially outside of a clinical trial should immediately discuss this new information with his or her doctor.

IMF Info Line – If you or someone you care for has Myeloma, you have questions. Probably, lots of them. You can search the Internet all you want, but other than asking your doctor, there is no better way to get your questions answered than to call the IMF Info Line. Missy, Judy and Paul know their stuff and they want to share what they know with you. Just ask anyone who has called the IMF Info Line. Patients or caregivers are welcome to contact the Info Line staffed by trained specialists at 800-452-CURE (800-452-2873). The Info Line is staffed between 9am and 4pm Pacific Time, 11am to 6pm Central time or infoline@myeloma.org.

The Trillium Fund was established by our founding support group members to facilitate Multiple Myeloma research here in Madison at the Wisconsin Institute of Medical Research. If you or your family wish to donate or send a memorial to this program, checks can be made payable to the "UW Foundation – Trillium Fund". Sean Lynch Director of Development UW Carbone Cancer Center University of Wisconsin Foundation 1848 University Ave Madison, WI 53726 (608) 422-1714 cell sean.lynch@supportuw.org

www.mycarbone.org has been established as an easier way to contribute. Check it out!